



Implementation of family awareness intervention program by parents with ASD children

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Abstract

ASD children experience different development with children in general, so that requires special services to optimize children's development, one of the factors that greatly contributes to determining child development is the family environment in which children live and develop. In certain places, parents of ASD children have not yet realized and understood the conditions of child development which are more likely to lead to ASD conditions so that parents have not been able to provide the best service according to their children's needs. Delays in intervening have an impact on the progress of children's development in the future so that the intervention program is the first step to providing the best service for children. There are two objectives in this study, namely to form a family awareness intervention program based on the needs of children and parents. Second, namely to describe the implementation of intervention programs carried out by the family to find out whether parents are able to properly implement the programs that have been prepared. The study was conducted using a qualitative approach, through five stages, namely the selection of cases, preliminary studies, assessment of family conditions and child development, formulating programs, and implementation. The resulting program covers aspects of knowledge, acceptance, and building family intervention skills on the child's condition. Program implementation shows that through programs that have been implemented, families know and understand the various symptoms of autism in children, and are able to provide interventions that are appropriate to the needs of children.

Keywords Intervention program · Family awareness · Children with ASD

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1 Introduction

Family concerns are key to monitoring child development and worry arises during the first 2 years of a child's life (Dosreis et al. 2006; Herlihy et al. 2013). Family sensitivity is often not accompanied by knowledge about ASD so the family is only aware of the delay in child development. Lack of family awareness occurs in families of children with ASD (Autism Spectrum Disorder), both those living in urban and rural areas (Heys et al. 2016). Families who are aware of children's development basically want to know the real condition of the child and the treatment that needs to be given so that the child can grow and develop according to his age. In rural communities, the lack of available information on various developmental barriers plays a role in the rapid pace of family identification of ASD children. The limited family knowledge about ASD children has an impact on the initial identification of the child's condition (Kusumadewi, 2013). Identification is the first step to understanding the child's needs relating to the services to be provided. Yuwono (2015) suggests that identification is a process that can be carried out by families, teachers, or experts to recognize the various delays associated with the child's condition. Identification of ASD children in various symptoms that appear before the age of 3 years, namely communication disorders, repetitive behavior, and low imagination ability, limited eye contact, limited empathy, and tendency to behave aggressively when disturbed (Buten 2005; National Research Council 2011).

Identification of ASD children was carried out using indicators of development of two-year-olds (Allen and Marotz 2010) and DSM V (5th ed.; DSM-V; APA 2013). Further assessment was carried out to determine the actual development of children and family conditions. The assessment results show that the family does not yet know the real condition of the child.

Based on these conditions, it is necessary to have an awareness intervention program that includes knowledge, acceptance, and building family intervention skills on the child's condition. Intervention skills are carried out by facilitating families to acquire skills in providing intervention to children so that families can provide early interventions that have an impact on children's development to be appropriate for their age.

Regarding the awareness intervention program for families with ASD children, George and Sakeer (2015) implemented a program on parental awareness of ASD conditions, difficulties in social interaction, speech and language, and motor skills. The results of the study indicate the occurrence of changes between before and after the implementation of the program in all aspects studied. Edwards et al. (2016) conducted a study of the importance of intervention for ASD children, namely the perspective of parents of children with ASD spectrum disorders. The results of the study indicate that interventions have a vital role to play in the family and the importance of collaboration between professionals and families in achieving successful interventions for children. The difference between this research and the research that has been done before, where this research is more focused on formulating programs designed with the family, and to find out whether the program formulation can be implemented by the family in serving the intervention needs of children.

2 Method

A qualitative approach raises various phenomena that occur in society (Satori & Komariah 2013). The use of qualitative research aims to obtain information about one’s perceptions and feelings that might influence behavior (Sutton and Austin 2015). The qualitative type used in this study is a case study, which is a study that studies about someone, a group of people or units (Gustafsson 2017). The selection of case studies is based on research participants consisting of a family and the researcher explores various information related to the research objectives as a basis for program formulation. Family determination is based on purposive samples, namely the determination of samples based on individuals with certain criteria so that they can assist in conducting research (Etikan, et al. 2016). The sample criteria in this study were families who realized that early childhood experienced developmental problems but did not yet know that the symptoms shown by the child caused the ASD condition. The research location is located in Cisarua Village, West Bandung Regency, West Java Province, Indonesia.

The first stage, namely the selection of cases consists of setting goals and determining the criteria of the sample in the study. Two things that become the process in selecting cases serve as a handle and guide for researchers in the process of preliminary study, assessment, formulating programs, implementing and analyzing program implementation.

The preliminary study phase consists of the process of identifying the subject, and confirming the subject. Identification aims to find subjects based on predetermined sample criteria. The identification process in the village of Cisarua was carried out through the village administrator, followed by finding data specifically to the family

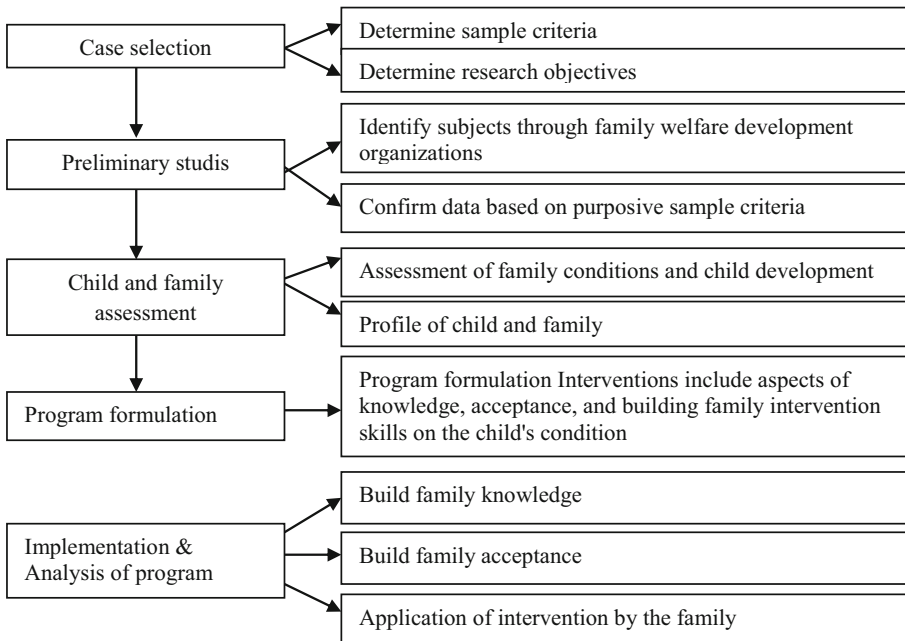


Chart 1 The process of formulating and implementing the program

welfare development organization in Cisarua village related to maternal and early childhood health problems which were thought to experience developmental barriers. The researcher made several visits to ascertain the information that had been obtained. The next step is to confirm with *bekunjung* directly to the family home that is suspected of having children with developmental barriers at an early age. The data confirmation process was carried out through family interviews, studies of child development documents originating from family welfare development organizations, documentation, family observation, and diagnosis of children's conditions based on DSM V and ICD 10 from WHO.

The next stage, namely the implementation of assessment which is also a demographic information on the family, aims to determine the developmental barriers that the child has and the needs of the family as shown by the child. These objectives were explored through interviews, observation and documentation. Interviews conducted were semi-structured to determine family conditions including knowledge of the condition of the child, family concerns about the condition of the child, family acceptance, economic conditions, history of the child's condition, care applied, and efforts made in optimizing child development. Observations made during the study were non-participant observation and participants. Non-participant observation aims to observe and record all parenting styles and the various phenomena shown by the family and children with ASD during the observation period. Participant observation is carried out through developmental assessment, the purpose of which is to determine the actual condition of the child's development. The documentation is done to complete data on family needs and the needs of children with ASD. The assessment results are then compiled into profiles of children and families, the profiles compiled consist of potentials or strengths that arise based on various things that are assessed, barriers or shortcomings of found conditions, and the needs of children and families for the conditions experienced.

The fourth stage is formulating the program, formulating the program based on the profiles that have been obtained. This stage aims to develop a program that can be used as a solution to problems experienced by children and families. Program formulation is carried out by researchers and families together. The last stage is the implementation of the program while analyzing the results of the implementation to find out the knowledge, understanding and skills acquired by the family after the program is implemented.

Data analysis was carried out descriptively to describe various things found during the research process, especially during the implementation of the program. The next step is to reduce data, present in matrix form or be verified (Miles & Huberman in Sugiyono 2012) so that it becomes the basis for describing the implementation of the program.

3 Result

The results of this study are to describe the results of program implementation that have been prepared by researchers and parents. Programs prepared are based on the needs of children and families. Family-resource intervention programs include knowledge, acceptance, and family involvement in the intervention of children with ASD. The aim of this program is to increase family knowledge and awareness of the importance of interventions according to the needs of children. The initial stage of this study begins with determining the purpose and criteria of the purposive sample, namely a family that has children at an early age, but does not yet know that the condition of child development

leads to developmental barriers. The purpose of the results of the research is to formulate a program that is appropriate to the needs of children and families, and describe the results of the implementation of the interventions that have been carried out by parents.

The second stage is conducting a preliminary study consisting of identification and confirmation activities. The results of identification of the subject is the discovery of families that meet the criteria of the study sample, then the data that has been obtained is confirmed to ensure valid or not the data that has been obtained, and ascertain whether the condition of the subject in accordance with predetermined research criteria. Confirmation results indicate that the condition of the child and family is in accordance with the predetermined sample criteria, namely the child experiences developmental barriers at an early age and the family is aware of the different development conditions of the child, but does not yet know the actual child development problems.

The following step is doing assessment which covered some aspects of family and child barriers, strengths and needs, family concerns on child development, family acceptance, financial history, parenting-style that implemented, and efforts that the family conducted to optimize the child's development. The result of assessment has become a stepping stone to showing child and family profile, which includes strength, obstacles, and needs. In this study, the implementation of family assessment refers to Soendari & Mulyati (2010) and Krauss (2000), the results obtained are:

Table 1 Family assessment

Family Assessment Domain	Assessment Findings			
	Condition	Strength	Obstacles	Needs
Acceptance for speech disability	Accept the disability that the child has	Understand child communication	Not trying to know the condition of child development and handling	Requires information on the obstacles and needs of the child in speaking
Acceptance of impairment Other developments (social & emotional)	Worrying, but accepting any conditions in children	Accepting regardless of the condition of the child even though not yet know the child has autism	Lack of motivation & knowledge even knowing children are experiencing developmental obstacles	Providing motivation and knowledge about the child's condition
Protection	Very loud and worried when the child is left alone so that the mother is always accompanying the child	Attention to the child	Less letting children explore the environment	It should give children a chance to explore the environment
Social Interaction	Less involving children in interacting with peers (the child is always in the house)	Mom has free time to be with the child	Lack of stimulus interaction of children from the environment outside the family	Allowing children to be in a social environment other than family
Fulfillment of Children's Needs	Attention to the child	Trying to meet the needs and whatever the child wants	Children look less independent	Must familiarizes for children to start independently especially on daily living activity

Developmental assessments are carried out on all aspects of development (motor, cognitive, language, social, and emotional) using child developmental tasks at the age of 2 years. Here are the results of child development assessments:

- a. Children has good rugged motor skills, such as walking more upright and throwing large balls with low swings, while fine motor skills that have not been mastered.
- b. Some of the cognitive abilities that children have not mastered are simple directives and instructions and do not show well-coordinated hand and eye movements, whereas some of the tasks that are mastered are expressing pain and gazing for a long period of time as seem interested.
- c. Speech and language abilities had not been mastered such as not realizing the importance of language for communication, using 50–300 different words, and using 3–4 words to speak, while the ability that the child controls only utters words that are only understood by himself. The researchers examined the child's development using a list of 1-year-old developmental tasks, the results of several developmental tasks that have been achieved, such as appointing a person / object and saying simple words (daddy, mommy, and aa).
- d. There were many personal-social development tasks that have not yet been achieved that show empathy and caring for others, and did not use physical aggression if angry, while some of the capabilities of development are expressed frustration by crying and showing impatience when wanting something. Researchers then use a list of tasks of social development at the age of 1 year, at this age there are many tasks of child-controlled development, such as not worrying about strangers and playing alone in the short term.

The fourth step was to design family awareness intervention program to ASD's child that implemented by parent. The program is carried out in three stages. The first stage was to build knowledge about ASD symptoms of autism delivered through a poster titled "Get to know Autism". The poster contains various symptoms of ASD that we need to be aware early on. The program implementation procedure is carried out for 15 minutes, with sharing and discussion methods done with family. The first stage evaluation is done by conducting an interview to know the response from the family regarding the symptoms of autism that the children have. The second stage was to build family acceptance of ASD that children have. The media used is visual technology, in the form of a video with theme "parents' experiences of child with ASD" in duration of about 30 min. The video told about the experience, views, and solutions provided by families of two children with ASD. Evaluation at this stage is carried out through interviews with family through responses given. The fifth was family involvement in implementation of program. The program that have been carried out, there was an implication that arises from the emergence of family motivation to provide intervention as early as possible both independently (train children's eye contact) and through growth and development clinics to minimize the visible symptoms, that children's development could be better.

4 Discussion

The goal of family awareness intervention program, is to increasing family awareness in providing intervention to child, which include to build knowledge, to build acceptance and to involved family in implementation of this program. Knowledge will bring acceptance so that there is an improvement in self-competence, especially in accepting the children condition. Some families of children with ASD were not aware of the children's condition, in particular in the early stages of child development (Bashir et al. 2014; Zaki and Moawad 2016). Based on this condition, the need to make families aware was a crucial step to take. This family awareness intervention program with ASD child is not solely based on the views of the research team, but came from the family's need to know the real condition of the child.

The Family Awareness Intervention Program also covered three aspects. First, building parental knowledge of people with autism and second, relating to family acceptance of the condition of autistic children. This program was based on the idea that building knowledge is the key to providing awareness in understanding children's conditions (George and Sakeer 2015; Surmen et al. 2015). The main goal is for families to recognize the diversity of symptoms of autism and have the ability to identify symptoms of autism. Efforts to achieve these objectives were carried out using visual media, in the form of poster presentations.

The poster used by the researchers had various images and explanations about various symptoms of ASD so that the content contained on the poster made it easier for the family to know the condition of the child because information related to the identification of ASD children was given simply and informally (pictures and writing). Rowe and Ilic (2009) stated that building knowledge can be done through various media, and posters are one of them. This is in line with George and Sakeer (2015) that as a visual media, posters are able to convey various messages without needing to be intervened by others.

Building family acceptance was a follow-up of knowledge building programs. The goal was for parents to be able to accept the condition of their children. The efforts made in this program were to try to facilitate meetings between parents and members of the parents of Indonesian disability children in West Bandung district to provide education, share experiences, consultations so that families understand, accept, and are able to apply appropriate parenting, but the planned effort apparently did not work as expected. Other efforts taken by researchers are utilizing technology products in the form of audio-visual media, namely video as a source that is seen as representing the process of intervention in family understanding and acceptance because content on audio-visual media (video) is informative and can build parents' acceptance of their child's condition.

The video used by researchers presents various information about autism and the experience of a family in raising an ASD child. The experience of parents with ASD children includes the problem of acceptance of the child's condition, the application of appropriate parenting and the importance of intervention as early as possible according to the needs of the child. The main purpose of using video is for families who are the subjects of research to be able to take the positive things shown in the video.

The next step was family involvement in implementation of the program. The impact of the implementation of the activity at building acceptance, it can be concluded that the family knows the variety of information relating to ASD and can take an attitude towards

the acceptance of the actual condition of the child. The effectiveness of the video influences the behavior of parents when dealing with the symptoms of autism shown by the child, such as difficult to build eye contact, difficult to communicate with, too focused on one object, and looks engrossed with oneself. These facts are understood by the family as a condition that often occurs in children, and this indicator is part of a parent's understanding. In accordance with this, providing knowledge to parents with autistic children has a positive impact on increasing understanding of autistic children and increasing coping and child and parent interaction (Preece and Trajkovski 2017).

Video is a popular technology that has the advantage of presenting a variety of information, messages, or instructions so that it can be aimed at parents (Goldsmith and Leblanc 2004) to consciously increase knowledge (Shabiralyani et al. 2015), and offer solutions to problems related autism (Azer et al. 2018; Schmidt et al. 2016). The use of video as an audiovisual media in this study shows that the provision of education cannot be separated from technology, because technology provides convenience in various aspects of life, one of which is as a substitute for obtaining a variety of information that can present facts in a real way. This is relevant to what was revealed by Sukma (2018) that audio-visual media such as videos are able to present a description of real events to be known and understood by others at a short distance.

June et. al. (2014) explained that videos are able to provide a stimulus to others and improve critical thinking skills. The implication of the use of audiovisual media is the response shown by the subject, namely the motivation to look for other sources related to ASD problems and begin to provide intervention by involving children in the growth clinic and parents' desire to be able to provide intervention at home. Based on family understanding gained through video, building eye contact is an intervention that must be given at home, and this ability is key in providing other interventions because there are many therapeutic activities for ASD children that are initiated through eye contact. This effectiveness can be seen from the increase in children's social eye contact (Rollins 2017). Child eye contact training is done by presenting a therapist, this process is carried out so that the family can gain understanding and skills directly in the way the therapist exemplifies how to develop children's eye contact through the ABA method by utilizing an object, in the form of a house key. The therapist also tells the family to always record the duration of the child's eye contact through the use of objects that the child enjoys in assessing the progress of eye contact. The presence of a therapist in the subject's home is also documented in the video so that it is easier for parents to remember the things that have been taught.

Furthermore, parents practice it themselves, both mentally and independently to build eye contact with children by using the key as the therapist does and always record the duration of eye contact the child shows. Eye contact training is carried out so that parents can carry out eye contact training in children so that it impacts on children's social development because eye contact is one part of social interaction (Allen and Marotz 2010).

5 Conclusion

The Family Awareness Intervention Program was consists of many steps. For the first step was identification, assessment to family and child. The following step include

designing the program and implementaion the program by family. In lasts, this program help family with ASD'child solve problems that their faced related to ASD. The family had knowloedge about autism and the symptoms, could accept the child's condition, and get involved in implementaion of intervention. This research more focused on early child with ASD, so far the next reseacrher could conducted with more mature child with ASD.

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